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ABSTRACT

The document presents a Department of Health, Education and Welfare (HEW) special report on dental care for the handicapped. The nature and extent of the problem of providing dental services to the handicapped population is examined. The handicapped population is defined and their oral health status reviewed. Factors contributing to the poor oral health of the handicapped are considered. Current HEW programs impacting on dental care for handicapped people are described, including those in the Health Care Financing Administration, Office of Education, Office of Human Development Services, and Public Health Service. Nine areas needing strengthening or improvement are discussed, including the coordination of federal activities related to the oral health of the handicapped and the training of dental students and practicing dentists in the care of handicapped persons. Fourteen suggested actions for the department are offered, including the establishment of a focal point within the department for activities relating to the oral health of handicapped people, and changes in the Medicaid law and/or regulation. (DLS)

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SPECIAL REPORT ON DENTAL CARE FOR HANDICAPPED PEOPLE

U.S. PUBLIC HEALTH SERVICE
AND
OFFICE OF HUMAN DEVELOPMENT SERVICES
DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

DECEMBER 1979

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This report was prepared by an ad hoc work group established by Dr. John C. Greene, Deputy Surgeon General and Chief Dental Officer of the United States Public Health Service. The work group consisted of:

Dr. John D. Suomi, Chairman, Dental Affairs Staff, OASH

Dr. Merle G. McPherson, Bureau of Community Health Services, HSA

Mr. Scott McGuire, Rehabilitation Services Administration, OHDS

Dr. Richard Melia, Rehabilitation Services Administration, OHDS

Dr. Alan Sandler, Bureau of Health Manpower, HRA

Dr. Clifford Scharke, Bureau of Health Manpower, HRA

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Executive Summary

Handicapping may be described as a chronic physical, mental or emotional condition that limits an individual's ability to perform activities appropriate to his or her age group. Handicapped people represent a large and diverse group numbering about 33 million in the United States. Although the oral health status of the handicapped population cannot be precisely defined, it is known that this group has proportionately greater dental treatment needs and receives less dental services than the "normal" population. Many handicapped people face barriers to dental care posed by the cost of dental services, transportation difficulties, poor design of buildings and dental offices, and difficulties in identifying and securing a source of dental care.

Congress has authorized several different programs whereby the Department supports activities to improve and expand dental services for handicapped persons. Among these are programs such as Medicaid, Head Start, Maternal and Child Health and Crippled Children's Services, Developmental Disabilities, Vocational Rehabilitation, EPSDT, National Health Service Corps and Community Health Centers. Not all of these programs have a specific focus on handicapped people, but they do provide dental services for handicapped as well as non-handicapped individuals. Additionally, several training programs for dental students and dental auxiliaries are being supported.

It is difficult to determine the full impact of these programs on the dental needs of handicapped people because the necessary data are not being collected on a routine basis. Among the areas that appear to need strengthening or improvement, however, the following may be cited:

- coordination within the Department of activities relating to the oral health of handicapped persons,

- training of dental students in the care of handicapped persons,

- access of handicapped persons to private dental offices,

- institutional dental facilities used to treat handicapped persons,

- access of needy, handicapped adults to dental services under Medicaid,

- financial renumeration of providers of dental services to the handicapped,

- educational and informational programs for handicapped persons, their parents or guardians, health care providers, and others in frequent contact with handicapped individuals,

- access of handicapped persons to dental disease preventive measures,

- hospital and/or dental school based treatment programs for handicapped people,

o research and development relating to the oral health of handicapped persons, and

o training of dental school faculty, dental hygienists, and auxiliaries in the care of handicapped persons.

Remedial actions that are being proposed include:

o establishment of a focal point within the Department for activities relating to the oral health of handicapped persons in order to improve coordination of such activities among the different agencies and components of the Department,*

o support for a program of dental student training in the care of handicapped people in each dental school in the United States,*

o support for the remodeling of selected private dental offices, and the upgrading of institutional dental facilities for the purpose of making those facilities more accessible to handicapped persons and capable of offering dental services to them in a safe, humane, and dignified manner,*

o changes in the Medicaid law and/or regulations to provide for greater financial incentives for dentists who treat Medicaid-eligible patients, and the provision of dental services for needy, handicapped adults as a mandated, rather than an optional, service,*

*Actions deemed to be of highest priority are indicated by an asterisk.

o support for and implementation of dental health educational and informational programs for handicapped persons, their parents or guardians, health care providers, and other persons in frequent contact with handicapped people,*

o support of dental disease preventive measures such as community and school fluoridation, supplementary fluoride use, and instruction in oral hygiene, diet and nutrition,*

o support for the development and expansion of hospital and/or dental school based treatment programs for handicapped people,*

o support of research and development relating to the oral health of handicapped people,*

o support of training programs in the care of handicapped persons for dental school faculty,* dental hygienists and auxiliaries,

o financial incentives for dentists to attend continuing education courses on the care of handicapped people,

o support for symposia conferences, and workshops dealing with the oral health problems of handicapped people,

- support for the development of directories of treatment and transportation resources for handicapped persons,

- support for the creation of a centralized system to monitor and evaluate progress being made in improving the access of handicapped persons to dental care.

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Introduction

A universally accepted definition of "handicapped people"* does not seem to exist. Generally, however, a person is considered handicapped if, due to a physical, mental, or emotional condition, he or she is sufficiently disabled so as to be unable to perform some or all of the activities considered normal for another person of the same age. This group is large and diverse and includes persons who are young and old, rich and poor, black and white, and institutionalized and non-institutionalized. Handicapped persons may be deaf, blind, mentally ill, mentally retarded, alcoholics, drug addicts, cerebral-palsied, epileptics and hemophiliacs — to name just some of the categories of individuals often identified as handicapped.

Because of the size and diversity of the handicapped population as a group, any recommendations designed to improve its access to dental care must be stated in broad and general terms. For example, an individual with a cleft palate may require a spectrum of medical and dental services vastly different from those needed by a hemophiliac individual and the approach to securing these services can vary. In the hemophiliac the scope of the dental services required may be quite similar to those needed by the average person, but the simple removal of a tooth is enormously complicated by the patient's underlying condition. To further complicate the picture, there are handicapped people who are unable

*The work group recognizes that persons with one or more disabilities are referred to as "handicapped" by others but not necessarily by themselves. The term "handicapped" has been used only because it is in common usage.

to cooperate in the treatment process. For example, the severely retarded individual may require general anesthesia in order for needed dental services to be received. In general, the specific functional limitations are more meaningful than diagnostic or other labels with regard to accommodations needed for dental care.

Compounding the problems of handicapped people in securing dental services are barriers posed by cost, immobility and transportation difficulties, ignorance, design of buildings and dental offices, fear (on the part of patients to receive treatment and dentists to render treatment), lack of know how by the dentist, and above average dental neglect and treatment needs. The list could go on. Some of the above barriers also apply to non-handicapped people, but they are almost universally applicable to handicapped people.

It may be appropriate to note at this point that although the dental problems of handicapped persons are seen as important by the work group, these problems may not be perceived in the same way by administrators of hospitals and institutions, officials of all dental societies, directors of rehabilitation programs, developmental disability councils, and other high level persons or bodies in positions to set policy and make decisions to improve the situation. Generally, dental problems are viewed as being at the low end of the totem pole by many persons who run large programs affecting handicapped persons. This report does not intend these comments to be critical, but rather, to point up the need for the education of persons in authority to the dental needs of handicapped persons.

Data of national scope that define the oral health status of the handicapped population, the number of dentists who treat handicapped people, and the number of handicapped individuals who receive adequate dental care are not available. Much of the information that is available comes from small studies and cannot be projected to the country as a whole. Other information comes from observations made by various individuals who either work with the handicapped population or have had occasion to visit an institution, school or work setting where handicapped persons are present.

The prevailing view is that handicapped people — particularly adults not in institutions — have great difficulty in obtaining dental services. It is with this view in mind that the work group attempts in this report to make recommendations to the Department for actions designed to bring about equal opportunity of access to dental care for handicapped people taking into consideration such things as (1) the costs — a major barrier for this financially overburdened group, (2) transportation and architectural barriers, and (3) deficits in training of dentists in the management and treatment of handicapped people. It should be noted, however, that any one of the various categories of the handicapped population could be the sole subject of an entire report. Perhaps, that is the next step in the process.

The present report is divided into four main sections: I. Nature and Extent of the Problem of Providing Dental Services to the Handicapped Population; II. Current Programs of the Department of Health, Education,

and Welfare Impacting on Dental Care for Handicapped People; III. Areas Needing Strengthening or Improvement, and IV. Suggested Actions for the Department.

Finally, it is recognized that not all recommendations for action presented in this report can be pursued. Neither does the report attempt to spell out in full how the recommended actions should be implemented.

I. Nature and Extent of the Problem of Providing Dental Services to the Handicapped Population

A. Description of the handicapped population

Handicapping may be described as a "chronic physical, mental or emotional condition that limits an individual's ability to perform activities appropriate to his or her age group"(1).*

Often, handicapped people are divided into two major subcategories: (1) persons with developmental disabilities and (2) persons with acquired medically related disabilities. The first broad category includes mentally retarded people — the largest group in this category consisting of about 6.5 million persons — and individuals with cerebral palsy, cleft lip and/or palate, epilepsy, autism and similar developmental disorders which originate at birth or in the childhood years. The second broad category includes individuals whose disability originates later in life due to injury, disease or dysfunction such as paralysis, rheumatoid arthritis, diabetes, multiple sclerosis, circulatory disorders, emphysema,

*For a comprehensive review of the problems relating to a definition of disability and handicap, interested readers are referred to a memorandum and attachments dated April 7, 1978, from the Assistant Secretary for Planning and Evaluation to the Secretary on the subject "Proposals to Reduce the Inconsistencies in Concepts, Criteria, and Definitions of Disability and Handicap -- Decision Memorandum." The review points out the value of defining disability in functional terms so that groups of individuals who share the same needs in mobility, self-care, communication, cognitive functioning and similar major life activities may be the focus of policies and programs.

renal failure, and mental illness. When analyzed in functional terms, these two groups share many problems of access to services. Each group also has unique characteristics.

It is estimated that there are about 33 million handicapped persons (as defined earlier) in the United States. This total is distributed across several handicapping conditions as follows: (1)

Mental Retardation	6.50 million
Cerebral Palsy	0.70 million
Muscular Dystrophy	0.22 million
Severe Hearing Loss	1.70 million
Severe Vision Loss	1.40 million
Total Paralysis	0.80 million
Rheumatoid Arthritis	6.00 million
Diabetes	0.60 million
Seizure Disorders	4.50 million
Multiple Sclerosis	0.45 million
Sickle Cell Anemia	0.25 million
Emphysema	1.30 million
Renal Failure	0.04 million
Mental Illness	9.00 million
Cleft Lip and/or Palate	0.12 million
	33.58 million

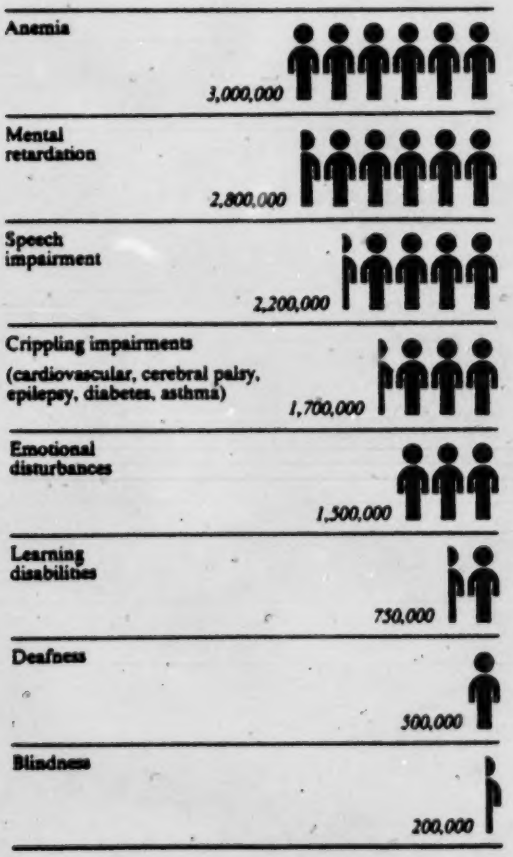
If we were to add to this total the number of persons having serious alcohol and/or drug problems, those incapacitated by cancer or cardiovascular disease, those with severe learning disabilities, and the elderly in nursing homes or homebound, the handicapped population would be greater — perhaps twice as many.

The 33 million figure represents about 15 percent of the U.S. population. Of these, about 2 million are in institutions, 2 million are confined to their homes, and another 2 million require special aids or another person to help them in moving about (1).

By age distribution, about 4 million are under 18 years of age, 18 million are between 18 and 64 years of age, and about 11 million are 65 years of age or older. The proportion of handicapped persons in an age group tends to increase by ascending categories of age (1). Approximately 60 percent of the handicapped population is in cities and the rest in small communities or on farms (1).

The table on the next page is reproduced from a Special Report on School Health Services published by The Robert Wood Johnson Foundation (Number One/1979) and presents prevalence data for major health problems of children under 21 years of age in the United States. The sum total of children affected by the particular conditions noted is over 12 million although more than one condition may be present in some children. Although many of these children may not be handicapped in the sense we have defined it, these conditions have the potential to substantially limit a child's ability to perform activities appropriate to his or her age group.

Health Problems of Children in the U.S.[1]
(Base: 76.1 million under 21 years)



1. Data are from *Report of the Harvard Child Health Project Task Force. Toward a Primary Medical Care System Responsive to Children's Needs.* Cambridge, Mass: Ballinger Publishing Company, 1977. Pertinent data are found in Volume I, Chapter 3 ("Changing Patterns of Death and Illness Among Children") and Volume II, Chapter 3 (Starfield, Barbara. "Health Needs of Children").

B. Oral health status of the handicapped population

Handicapped persons, on the whole, have generally been found to have a poorer oral health status than non-handicapped persons (2). Many handicapped persons have had little or no dental care or have received only emergency care (3). The level of oral hygiene in these persons is often unsatisfactory. As a result, periodontal disease is a common problem among handicapped people. Patients with Down syndrome, in particular, often have a low incidence of caries, but an unusually high degree of periodontal disease (4). Alveolar bone loss in these patients is generally severe — especially in the lower anterior region.

Specific studies show:

(1) Among one group of 201 mentally retarded children between 3 and 14 years of age, 55 percent had unfilled cavities and 47 percent had never received dental care (5).

(2) In a group of 113 non-institutionalized mentally retarded children between 1 and 19 years of age, 42 had never been to see a dentist, and of the remainder, only 50 percent had had any work done which was usually of an emergency nature (6).

(3) A group of 411 orthopedically handicapped children (age not given) had a significantly higher decayed, missing and filled teeth rate and periodontal index than a "normal" control group (7).

(4) In a prototype community dental treatment program for 165 handicapped children and a few adults ranging in age from 3 to 30 years, those receiving services had treatment needs averaging over ten restorations and extracted teeth per person (8).

C. Factors contributing to the poor oral health of the handicapped population

1. Lack of an organized plan in the community

In many communities, there is no organized plan to address the dental needs of handicapped people. In addition, many parents of handicapped children are apathetic or fail to realize the importance of regular dental care. In 20 communities in which the National Foundation of Dentistry for the Handicapped (NFDH) established or attempted to implement dental programs:

> "an organized plan addressing the dental needs of disabled persons had not been developed prior to NFDH assistance. Professional resources had not been mapped out. . . Moreover, before becoming involved with the Foundation, none of

these communities had organized preventive dentistry and screening programs in the educational, vocational, and residential centers serving the area's handicapped citizenry. As a result, the oral health status of this disadvantaged population has suffered. Even when care has been rendered, it has often been when a crisis situation developed; after pain or facial disfigurement has occurred" (2).

It is therefore, important that provisions for meeting the dental health needs of all individuals, including handicapped persons, be incorporated into the goals of each Health Systems Agency's Health Systems Plan.

2. Many handicapped persons are unable to obtain dental treatment

Among the reasons for this situation, the following may be listed:

a. Sensitivity and Perceived Ability of the Dentist - Handicapped individuals have difficulty in identifying a dentist who is both willing and able to provide dental treatment for a handicapped person. Dentists cite reasons such as lack of training, problems of patient management, and income not commensurate with the time and effort expended for their unwillingness to treat handicapped people (9).

b. Architectural Barriers - Many dental offices are unreachable to handicapped people because of physical barriers such as steps, narrow doorways, and small

operatories in which it may be difficult to maneuver in a wheelchair (10). Hitherto, most practitioners have not considered the problems of handicapped people in designing or locating their offices. It has been estimated that as many as 75 percent of dental offices have architectural barriers.

c. Transportation - Although some handicapped people are able to drive a car, many cannot do so and are dependent on another person to provide the transportation they need. Public transportation, for the most part, will not accommodate wheel chairs. Or, if public transportation is available and can accommodate the handicapped person, it may not take him or her to the particular location at which needed dental or medical services are provided. Because of these transportation difficulties many handicapped persons do not receive health care services on a regular basis.

d. Finances - Handicapped people often lack sufficient financial resources to pay for dental treatment. Handicapped patients often require "special handling." For example, pre-medication and/or inhalation sedation are often required in the provision of routine dental services (9). Other more exacting procedures may have to be provided under general anesthesia. Dental treatment provided under these conditions is usually more expensive than when such measures are not required.

Each state, except Arizona, provides dental benefits for Medicaid-eligible children under the EPSDT program. Only 37 states, however, provide some form of dental services to adults under the Medicaid program (11). In addition, many disabled individuals or their parents or guardians do not know that they may be eligible to receive these services. Furthermore, because there are inadequate reimbursement schedules for Medicaid providers in many states, some dentists do not accept Medicaid patients.

e. Individual and Parent Sensitivity - Many handicapped individuals lack knowledge of the importance of dental health. The same is often true of parents at home and staff working in an institutional setting. It is not unusual to see a handicapped child being rewarded with candy for positive behavior. Proper information must be provided which discourages this type of unhealthy practice.

It should be noted that the barriers to receipt of dental treatment faced by handicapped persons may vary depending on the nature of the handicap. In addition, the individual treatment needs of handicapped persons also vary. Some handicapped persons may require only a slight degree of assistance, or need to overcome only minor barriers, in order to receive needed dental services. Others may have to face up to most or all of the barriers to care that have been enumerated. In the latter situation, the cooperation of the federal, state, and private sectors is essential to ensure that proper care may be received.

3. Inadequate application of dental disease preventive measures

Only about one-half of the U.S. population has access to fluoridated water. This preventive measure alone, if available to children from birth, can reduce dental decay by about 50 to 70 percent. Additionally, certain supplemental fluoride regimens that are quite effective in preventing dental decay among school-aged children may not be appropriate for all handicapped children. For example, fluoride mouth rinses are now being used in many schools throughout the country. Yet, the handicapped person may have trouble swishing or expectorating the fluoride solution.

To further compound the problem, many handicapped people (and those who care for them) lack the knowledge and skills necessary to prevent oral disease through such measures as fluoride supplementation of the diet (in non-fluoridated areas), and proper nutrition and oral hygiene procedures. Additionally, the handicapped individual may be physically unable to use the devices for cleaning his/her teeth that are easily used by the non-handicapped person. There is a need for development and widespread marketing of adaptive dental devices for handicapped people.

4. Institutional shortcomings in providing dental services to handicapped people

Physically-handicapped and mentally-impaired persons who are confined to long-term care institutions are generally provided dental services, as needed, in clinical facilities at the institution by dentists employed for this purpose.

In spite of the fact that most institutions for handicapped people offer some type of dental service, the oral health status of many residents is poor. Surveys have shown that most institutionalized patients have poor oral hygiene and almost half have some type of dental problem (2). This is true in part because such institutions generally house the most severely handicapped people who cannot manage their own oral hygiene needs. Staff to resident ratios are often such that staff does not have the time (nor the training) to assist the residents in this endeavor. Oral hygiene supplies may be limited because of budgetary restrictions.

Although institutions for handicapped people should have the services of dentists with special training in the care of persons with disabilities, many do not have dentists with such training. Furthermore, the dental facilities at many institutions lack the sophisticated, modern equipment needed to provide dental services in a humane, safe, and dignified manner.

II. Current Programs in the Department Impacting on Dental Care for Handicapped People (12)

The Congress has authorized several different programs whereby the Department can support activities to improve and expand dental services for handicapped persons.

The programs described below have a focus (a Congressional mandate or a program emphasis) which relates to the provision of dental services to handicapped people; the training of dentists or dental students in the management and treatment of the handicapped patient; and/or research, demonstrations or other special projects to improve the dental health of the handicapped population. Not described are several Departmental programs which do not have a specific focus on handicapped people but probably do support the provision of dental services for handicapped as well as non-handicapped individuals. Such programs include the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) component of the Medicaid program, the National Health Service Corps, and the Community Health Centers program.

A. Health Care Financing Administration

The Medicaid program is a joint federal/state program financing a wide range of health services for cash assistance recipients (age 65 or over, blind, permanently and totally disabled, or members of families with dependent children)

and, in certain States, for other medically needy persons who except for the fact that they have income and resources above a certain minimum level would be eligible for cash assistance. Eligibility is determined by the state in accordance with federal regulations. States are not required to provide dental services except to individuals under 21 years through the EPSDT program component of Medicaid. (Authority: Social Security Act, Title XIX)

About 37 states provide some form of dental services to handicapped adults (i.e., those who are eligible for Medicaid because they are needy and either blind or permanently and totally disabled). Expenditures for dental services for the blind and disabled account for about 1.4 percent of total Medicaid expenditures, and about 10.5 percent of total Medicaid expenditures for dental services. The Federal share of Medicaid expenditures for dental services for blind and disabled persons was estimated to be about $23 million in FY 1977.

B. Office of Education*

A formula grant program provides support to improve state and local educational management capabilities, including comprehensive planning and evaluation. (Authority: Elementary and Secondary Education Act)

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*Recently, Congress established a separate Department of Education.

Most of the funds are awarded on a competitive basis by state and local education agencies to provide support for supplementary educational centers and services, innovative projects, dropout prevention projects and strengthening state and local educational agencies. Fifteen percent of these funds must be spent on special programs and projects for the education of children with specific learning disabilities and other handicapped children.

Dental services for handicapped children may be supported under this program; however, it is not known if any of the states are providing such support.

C. Office of Human Development Services

1. Special programs for the aged—

Title III Section 308 model projects on aging

One of the objectives of this grant program is to support projects that develop, demonstrate, or study new and innovative methods, techniques or approaches designed to coordinate the community's various social, health and welfare services so as to increase their efficiency for older people. Any public or non-profit agency, institution or organization engaged in activities related to serving the needs of older people is eligible for project support. (Authority: Older Americans Act of 1965 as amended by P.L. 90-42, 91-69, 92-258, 93-351, and 94-135)

Meeting the needs of physically and mentally impaired people is one of several program priorities. Projects to improve dental services for elderly handicapped persons could be supported under this program; however, no such projects are being supported.

2. Head Start

This program provides project grants to eligible public and private non-profit agencies to operate programs which provide education, health and social services to mostly poor children 3 through 5 years of age, and involve parents. (Authority: Head Start, Economic Opportunity, and Community Partnership Act of 1974)

No less than 10 percent of the total number of enrollment opportunities in Head Start programs in each state must be available for handicapped children and services must be provided to meet their special needs. By 1978, all but one of the 50 states had met or exceeded this 10 percent requirement. In that year, there were 38,121 handicapped children serviced in reporting Head Start programs.

Every handicapped Head Start child receives basic dental care services including preventive services, just as non-handicapped Head Start children do. In addition, Head Start children with handicapping oral conditions, such as

cleft lip/palate, are supposed to receive needed specialized rehabilitative services. In 1978, cleft palate was the primary specific professionally-diagnosed handicapping condition of about 385 Head Start children. The number of Head Start children who receive rehabilitation services for oral handicaps is not known.

3. Developmental disabilities--basic support and advocacy grants

This formula grant program assists states in the provision of comprehensive services to assure that persons who have a mental and/or physical disability which results in a substantial impairment manifested before age 22 are enabled to achieve their maximum potential. The program impacts on an estimated 10 million developmentally disabled persons. (Authority: Mental Retardation Facilities and Community Health Centers Construction Act of 1963 as amended by P.L. 90-170, 91-517, 94-103, and 95-602)

Dental services may be supported under this program. State plans in at least six states (Colorado, Louisiana, Massachusetts, Michigan, Missouri and New Jersey) are known to specifically include dental services. States are required to assure that every institutional or community-based resi-

dential program for developmentally disabled persons supported under this program will provide such persons with appropriate and sufficient dental services. The extent to which dental services are actually provided through this formula grant program is not known.

Colorado, Louisiana, Michigan and New Jersey provide additional state funds specifically to support dental services for developmentally disabled persons.

4. Developmental disabilities--special project grants

This program provides grant support for projects to improve the quality of services to the developmentally disabled. States, political sub-divisions of states, other public agencies and non-profit organizations are eligible to receive grant support. (Authority: Mental Retardation Facilities and Community Health Centers Construction Act of 1963 as amended by P.L. 91-517, 94-103 and 95-602)

Four supported dental projects were active in FY 1978 and two of these continued into FY 1979:

Regional Dental Care Center for Technical Assistance in Training. This University of Iowa project is designed to (1) establish a regional dental center to provide training and technical assistance to dentists and auxiliary personnel in dental

treatment of individuals with developmental disabilities; (2) establish a series of model preventive dentistry programs in regional residential facilities, public schools, and sheltered workshops; and (3) develop and publish a pamphlet on dental care for the handicapped. The project period is from September 30, 1977-September 29, 1981. Through FY 1978, $186,216 in grant funds have been awarded.

Campaign of Concern. Funds were provided to the National Foundation of Dentistry for the Handicapped to support the Foundation's Campaign of Concern which aims to improve the oral health status of developmentally disabled persons. Grant support was provided for the following specific activities: (1) establish coordinating committees in ten cities; (2) identify the dental needs of disabled people in the ten areas; (3) develop a program to meet identified needs; (4) produce slide/tape presentations to inform dental professionals, including students, on developmental disabilities and the needs of handicapped persons as related to dentistry; and (5) create a dental education advisory committee, comprised of educators from five dental schools, to assess what education experiences in dentistry for the handicapped are being provided to dental students. The project period was from June 30, 1975-June 29, 1979. A total of $245,111 in grants was awarded for this project.

Dental Care Program for the Developmentally Disabled. This Mount Zion Hospital project was designed to improve dental care for persons with developmental disabilities in the San Francisco area through the following activities: (1) screening and referrals for treatment for those with dental disease; (2) provision of preventive oral health education at community agencies; (3) direct dental treatment for those with severe disabilities; (4) training of dental residents in all phases of dental care for the developmentally disabled; and (5) offering of post-graduate courses to dentists in subjects relevant to dental care for the disabled. Dentists practicing in the community were afforded the use of hospital facilities and training to provide services to severely handicapped dental patients with severe dental problems. The project period was from June 30, 1975-June 29, 1978. A total of $117,000 in grants was awarded for this project.

Training of Developmentally Disabled Individuals in Dental Aide Skills. This University of Pennsylvania, School of Dental Medicine, project was designed to (1) train persons with developmental disabilities in skills necessary to provide dental aide services and (2) place these individuals, following training, in gainful employment within the community and local dental facilities. The project period was from June 30, 1975-June 20, 1978. A total of $186,234 in grants was awarded for this project.

5. Developmental disabilities--university-affiliated facilities*

This program provides project grant support to assist with the cost of administration and operation of facilities for (1) providing interdisciplinary training for personnel concerned with developmental disabilities; (2) demonstrations of the provision of exemplary services related to the developmentally disabled; and (3) demonstration of findings related to the provision of services. (Authority: Mental Retardation Facilities and Community Health Centers Construction Act of 1963 as amended by P.L. 91-517, 94-103 and 95-602)

Of the 37 university-affiliated facilities receiving support under this program in FY 1979, 23 facilities have components related to dentistry for developmentally disabled persons.

6. Rehabilitation services and facilities--basic support program

This formula grant program provides support to the states for vocational rehabilitation and related services and for assistance in the construction and establishment of rehabilitation facilities. Individuals eligible for services under this program must have a disability which is a significant handicap to employment. (Authority: Rehabilitation Act of 1973 as amended by P.L. 93-516, 94-230 and 95-602)

*It should be noted that some university-affiliated facilities receive support from the Bureau of Community Health Services, Public Health Service.

The need for treatment of routine dental conditions involving caries, abscesses, extractions, or provision of dentures does not, by itself, meet vocational rehabilitation eligibility requirements.

The consideration of dental conditions, per se, as significant handicaps to employment has been in a downturn in vocational rehabilitation agencies since the passage of the Rehabilitation Act of 1973 which established first priority for serving severely handicapped individuals. In FY 1977, only 3.5 percent of all persons rehabilitated had dental conditions as their major disabling condition (9,685 persons). Of the 55 state agencies reporting in FY 1977, 25 reported less than one percent of their rehabilitations from this group. It is assumed, moreover, that these cases involve severe oral problems related to vocational outlook or associated with other vocational limitations.

Rehabilitation agencies may provide dental services to clients whose major disabling condition is unrelated or only indirectly related to the oral health area, but whose need for dental care is related to their vocational goal. Thus, rehabilitation counselors and facilities may authorize and provide the dental evaluations and services needed to establish an acceptable level of oral health in an individual who has neglected dental care to the extent that his chances of obtaining a job or maintaining an acceptable health level may be adversely affected.

Such policies and care decisions would be up to individual counselors working with state agencies, however. Federal policies do not, at present, advocate dental services with a preventive orientation, referral, or treatment for disabled persons served by states under the vocational rehabilitation program.

7. Independent living

Rehabilitation for independent living is a relatively new and expanding area. Under the administration of the Rehabilitation Services Administration, a new provision in law allows funding of independent living centers within states to promote enhanced self-care of severely handicapped individuals in the community. Guidelines and project awards are very recent. While dental care has received little attention as an aspect of independent living, at least one dental school (University of Washington) has been working in an outreach fashion, using dental hygienists in the independent living setting to teach preventive care, and linking teaching efforts to independent living needs through the clinical practice in its post-graduate program. (Authority: Rehabilitation Act of 1973 as amended by P.L. 95-602)

8. Rehabilitation training

This program provides support for training to increase the numbers of personnel trained in providing vocational rehabilitation services to handicapped persons. Grants and contracts may be made to state vocational rehabilitation agencies,

and other public or nonprofit agencies and organizations including institutions of higher education. (Authority: Rehabilitation Act of 1973 as amended by P.L. 95-602)

In FY 1979, four dental training projects related to the rehabilitation of handicapped persons were supported. Franklin Institute in Philadelphia provided training to dentists and dental assistants in the various modes of dental treatment for the severely handicapped patient. The University of Washington conducted an eight-week program of clinical training and didactic instruction for dentists, dental hygienists and dental assistants in dental care for the disabled. Training grants and traineeships were also provided to the New York University College of Dentistry and the University of North Carolina School of Dentistry, Chapel Hill. The trainees were graduate students in either prosthodontics, orthodontics, oral surgery or pedodontics. Training in clinical techniques, research and teaching was provided in a number of areas of dental rehabilitation according to the specialty area of the trainee.

9. Rehabilitation research and demonstrations

This program, now administered by the new National Institute for Handicapped Research, provides support for innovative research and demonstrations of regional and national significance that are designed to discover, test, demonstrate or promote the utilization of new concepts and devices which will provide rehabilitation services to handicapped persons. Grants and contracts may be made to states and nonprofit organizations. (Authority: Rehabilitation Act of 1973 as amended by P.L. 95-602)

Federally-supported Research and Training Centers at 21 major universities have supported studies in the past related to dental areas, but FY 1978 summaries of R & T Center projects listed no such efforts.

D. Public Health Service

1. General practice of dentistry residency training

This grant program aims to preclude overspecialization in dentistry and fragmentation in the delivery of dental care by supporting training which will provide dental residents with advanced skills and competencies in the general practice of dentistry. Project grants are made to dental schools and accredited postgraduate dental training institutions to develop and operate such residency programs and provide traineeships and fellowships to residents who are in need of financial help and who plan to specialize in the practice of general dentistry. [Authority: Public Health Service Act, Sec. 786(b)]

Advanced training for the dentist in the care of the handicapped individual is an integral part of general practice residency programs.

In FY 1978 and 1979, grant support was provided to 46 general practice residency programs in which 386 dentists were enrolled.

2. Maternal and child health and crippled children's services

This formula and project grant program includes support to state maternal and child health and crippled children's agencies for: (1) services for locating children who are crippled or who are suffering from conditions that lead to crippling and for all necessary diagnostic, treatment and aftercare services; (2) special projects of regional or national significance which may contribute to the improvement of services to mothers and children, including crippled children; and (3) services for promoting the health of mothers and children. (Authority: Social Security Act, Title V)

The Crippled Children's Services program, in particular, provides a significant national source for supporting dental/medical treatment and rehabilitation services needed by children with cleft lip/palate and other congenital and severely handicapping oral anomalies and conditions. In 1972, 25,047 children with cleft lip/palate received care under this program.

Three special project grants totaling $185,152 were awarded in FY 1979 for three service projects relating to dental care for handicapped people:

Project title	grantee	FY 1979 award
Cleft Palate	State Dept. of Health Helena, Montana	61,000
Dental Care for Retarded Children	State Health Dept. Rhode Island Hosp. Providence	63,500
Facial Deformities projects	State Health Dept. Richmond, Va.	60,652

Recent program evaluations include: An evaluation of pedodontic training programs, DHEW Publication No. (HSA) 78-5218, and an evaluation of state dental health programs for mothers and children. The latter will include an evaluation of services provided to children with handicapping conditions.

3. Maternal and child health and crippled children's services training

This program provides project grant support to institutions of higher learning to train personnel to provide health care and related services for mothers and children, particularly mentally retarded children and children with multiple handicaps. (Authority: Social Security Act, Title V)

In FY 1979, grant awards totaling $574,000 were made for six projects dealing exclusively with the training of pedodontists to serve handicapped children. In addition, 21 comprehensive interdisciplinary training projects that included dental components were funded. Eighteen of these projects involved the so-called university-affiliated facility programs that also receive support from the Rehabilitation Services Administration.

Additionally, four non-recurring grants totaling $75,000 were funded in FY 1979 for the support of workshops or conferences addressing such subjects as a symposium on preventive dentistry and the role of dentistry in the interdisciplinary treat-

ment of genetic disease. In FY 1978, seven projects totaling $121,000 were funded for similar meetings or workshops.

4. Maternal and child health research

This grant program provides support to research projects relating to maternal and child health services or crippled children's services which show promise of substantial contribution to the advancement of such services. Grants may be made to institutions of higher learning, state and local governments and other public and private nonprofit agencies and organizations. (Authority: Social Security Act, Title V)

Even though dental projects have been supported under this program in the past, no dental projects relating to handicapped people were supported with FY 1979 funds.

5. Comprehensive hemophilia diagnostic and treatment centers

This project grant program provides support to expand the nationwide availability of comprehensive outpatient diagnostic and treatment centers for persons with hemophilia, particularly in areas where there are the greatest number with severe or moderate cases of the condition. State and local governments and other public and nonprofit entities are eligible for support to initiate or expand such centers for hemophilia patients. (Authority: Public Health Service Act, Section 1131)

Twenty-three comprehensive hemophilia screening, detection and treatment centers are being supported under this program. An important required component of each of these centers is dental services. Efforts are also being made by many of the centers to train dentists within the state or local area to treat individuals with hemophilia in their own local practice area.

6. Craniofacial anomalies program

The National Institute of Dental Research conducts and supports research on craniofacial anomalies extending from the broad field of developmental biology to the clinical rehabilitation of the deformed. (Authority: Public Health Service Act, Sections 422, 423 and 472)

Clinical research supported by the Institute since 1959 has been instrumental in the development of advanced surgical techniques and trained clinicians to habilitate children with cleft lip/palate.

Even though the current emphasis in this program is on fundamental research on all types of congenital and developmental craniofacial anomalies, some clinical research related to cleft lip/palate continues to be supported. As an integral part of these clinical research efforts, some persons with severe oral handicaps are receiving care services.

III. Areas Needing Strengthening or Improvement

A. The coordination of federal activities related to the oral health of handicapped people

The Congress has authorized several different programs whereby the Department can support activities to improve and expand dental services for handicapped persons. In total, 16 such programs administered by the Department have been identified. Twelve of these programs were known to be supporting dental activities related to handicapped people in fiscal year 1979 (see Section II).

Generally, there is little coordination between all these various programs with regard to the components impacting on dental care for handicapped people. This may result in some duplication or omissions that perhaps, could be avoided if there were a focal point for dental care for handicapped people within the Department. In addition, there is little or no emphasis given to monitoring or documentation of expenditures, visits, patients, or health outcomes resulting from any one or combination of these programs. As a result, the

Federal Government cannot evaluate intelligently the appropriateness or results of its current programs or, with confidence, plan for future programs to improve upon the deficiencies and lack of coordination that surely exist.

B. The training of dental students and practicing dentists in the care of handicapped persons

Studies have shown that dentists' training experiences are closely related to whether or not handicapped persons are treated by dentists (13,14). If dentists have attended a post-graduate pedodontic training program, or received classroom education or clinical training in the treatment of handicapped people, they are much more likely to treat such patients in their practices. In most instances where a training program in the dental treatment of handicapped people was established, the dental school has become recognized in the community as a resource center for care delivery, information, and education relating to dentistry for the disabled patient (15, 16).

The Public Health Service in FY 1979 -- from Maternal and Child Health Title V funds -- awarded grants totaling $574,000 to six dental schools for training of pedodontists to serve handicapped children. Dental components were included in 21 additional comprehensive training programs also devoted to serving handicapped persons. The latter programs include 18 of the 23 university-affiliated facilities programs

identified earlier as receiving support under the Developmental Disabilities program of the Rehabilitation Services Administration, and as having dental components. In addition, four dental projects were supported by the Rehabilitation Services Administration for training dental personnel in the provision of dental treatment to disabled individuals.

It should be noted at this point that The Robert Wood Johnson Foundation in the recent past provided 4.7 million dollars for training of students in 11 dental schools to care for nonhospitalized handicapped persons (16). During the four years that support was provided, approximately 7,700 students were exposed to one or more years of teaching in the program and more than 4,000 students graduated having completed the program. Although this pilot program was judged successful in meeting its objectives, the committee that guided the program concluded that a national program for training all dental students in the care of handicapped persons was needed (16). A most encouraging feature of the programs supported by the Foundation has been the willingness of the dental schools involved to continue the training programs on their own since the support from the Foundation ended.

While the programs noted above indicate that progress in the training of dentists, dental students, and auxiliary personnel is being made, many dentists still graduate without having had any instruction in the provision of dental services to handicapped persons.

C. The remodeling of selected private dental offices and the upgrading of institutional dental facilities involved in the provision of services to handicapped people

It is estimated that as many as 75 percent of dental offices are inaccessible to handicapped people.* With regard to institutions caring for handicapped people many of their dental clinics are somewhat primitive when viewed against the dental operatory set-ups available in 1979 (2).

D. The provision of dental services for needy, handicapped adults as a required service under Medicaid and improved financial incentives to providers of dental services to Medicaid-eligible people

Under current authority (Social Security Act, Title XIX), states are not required to provide dental services to Medicaid eligibles except to individuals under 21 years of age through

*The work group determined that certain tax deductions are available to dentists and others for qualified architectural and transportation barrier removal expenses. The deduction is allowed for certain expenses for the purpose of making any facility owned or leased by the taxpayer for use in connection with his business more accessible to handicapped or elderly individuals. The amount deductible for any taxable year is limited to $25,000. (Federal Register/Vol. 44, No. 143/ Tuesday, July 24, 1979/Rules and Regulations) It should be noted, however, that this provision is due to expire on December 31, 1979, unless it is extended by Congress.

the early and periodic screening, diagnosis and treatment program (EPSDT) component of Medicaid. As a result, only 37 states provide dental services to adult, handicapped persons eligible for Medicaid under this statute and in six of these states, adult dental benefits are limited to emergency treatment (11). Furthermore, many dental practitioners are reluctant to treat any Medicaid patients (let alone handicapped Medicaid patients) because of poor remuneration schedules established by the states.

E. Educational programs for handicapped persons, their parents, and health care providers on the importance of dental care for handicapped individuals

There is a need to inform parents of handicapped people, persons who work on a daily basis with handicapped people, and health care providers other than dentists as to the need of this population for regular and adequate dental care and their need for daily oral hygiene procedures. Additionally, sources of financial support and dental services for non-institutionalized handicapped people need to be identified, publicized or centrally managed in an efficient manner.

Parent apathy in some areas has been so rampant that it has been necessary to bus handicapped children to dental clinics and, in some cases, obtain court orders so necessary dental services could be provided (2). Moreover, many communities do not have any provision for dental screening and preventive programs in the educational, vocational, and residential centers serving the area's handicapped citizens. Lastly, the public and private dental facilities equipped to provide dental services to handicapped people are often not known to parents or others who might be in a position to guide handicapped persons to such facilities.

The American Dental Association is currently compiling information on local and state health departments that provide dental services to handicapped people as well as programs developed by local and state units of the Association and private agencies. It should be noted, however, that the responses received by no means represent all programs in existence and further, that there is no attempt being made to validate the current operational status of these programs.

F. Access to dental disease preventive measures

Fluoridation of community water supplies began in the United States in 1945. Over 30 years of community experience has shown the benefits of fluoridation to be substantial. For children, the caries rate can be reduced by as much as two thirds. Yet, two of every five persons on community water systems are still being provided fluoride-deficient drinking water.

In FY 1979, the Department launched a fluoridation initiative designed to expand its fluoridation and technical assistance efforts and to provide grant support to states and communities to assist communities and schools to fluoridate their water systems if they should desire to do so. This is a major step in the right direction and this program should be supported until such time that all communities having public water systems will have the opportunity to fluoridate. There is, however, the need to offer alternative means of providing the benefits of fluoride to handicapped persons who live in areas that cannot be fluoridated or areas that choose not to fluoridate the community water supply. Specially designed oral hygiene programs for handicapped persons are also needed.

G. <u>The expansion of hospital and/or dental school based programs for treating handicapped people</u>

With the increasing trend of de-institutionalization in this country, more and more handicapped individuals are being returned to the community and, therefore, face the need for finding their own sources of health care, including a source of dental treatment. Even without this added burden, hospital dental clinics as presently constituted cannot cope with the needs for dental treatment of handicapped people (17, 18). Additionally, most dental school clinics do not accept handicapped people as patients unless the school is participating or involved in a special training program. Although the Department in past years has supported hospital and/or dental school based programs for handicapped people (Mount Zion Hos-

pital in San Francisco, for example), the support has been very limited both in terms of the number of such projects supported and the dollar amount of the grants awarded (12).

H. Research and development relating to the oral health of handicapped persons

The advisory committee to the Robert Wood Johnson Foundation found a need for an expanded research and development effort in the area of providing dental care to handicapped patients (16). It was stated that more needed to be known about treatment methodology, patient management, and the dental aspects of handicapping conditions. Additionally, it was determined that the organizational and management aspects of teaching programs in the care of the handicapped needed further exploration.

To these concerns may be added questions relating to adjunctive methods of fluoride use by handicapped persons and the best methods of oral hygiene for this population group.

I. Training of dental school faculty

The final report of the advisory committee to the Robert Wood Johnson Foundation identified still another critical problem — that of "the scarcity of faculty adequately prepared to teach dental students to care for the non-hospitalized handicapped (16)." The report points out that there is not one institution in the United States offering a training program of this nature.

Most faculty members involved in teaching in the foundation-sponsored programs of dental student training were dentists who had received specialty training in pedodontics or dentists with hospital experience. The committee report goes on to state that "neither of these training experiences is completely adequate for preparing faculty who are able to treat a full range of handicapping conditions in patients of all ages."

IV. Suggested Actions for the Department

A. Establishment of a focal point within the Department for activities relating to the oral health of handicapped people*

A focus for dental activities that impact on handicapped people should be established within the Department. It is also proposed that this setting be the focal point for all Departmental activities related to dental care of the elderly, persons confined to nursing homes, and the homebound.

Primary functions of this position would include:

o Acting in a liaison capacity between the Federal Government, the profession, dental schools, and institutions for handicapped people to ensure that federal resources and programs are made known and used to the maximum benefit of the handicapped population.

o Representing the Departmental view with regard to the care of handicapped people before professional and lay groups.

o Attempting to coordinate all dental activities related to handicapped people among the various agencies and components of the Department.

o Responding to all requests for information, consultation and assistance relating to the dental health of handicapped people.

*Actions deemed to be of highest priority are indicated by an asterisk.

B. Support a program of dental student training in the care of handicapped people*

Every U.S. dental school should provide undergraduate dental students with special training in the care of handicapped persons. At present, only about 11 of the 60 dental schools have developed specific training programs in this area. Justification for a federally-supported training program as proposed is provided by the remarkable impact which the Dental Auxiliary Utilization (DAU) Programs have had on the delivery of dental care in the private practice sector. Because most schools are short on financial resources, it is proposed that a grants program be established to make available support for this purpose to dental schools for a period of four years. Funds could be used to support personnel, purchase specialized equipment, develop teaching materials and to make limited modifications in facilities so handicapped patients can reach treatment areas. (See also item I. which speaks to the need to support faculty training in conjunction with the student training program.) Experience indicates that support for four years is usually necessary before a school is ready to continue on its own to teach students to care for handicapped people (16). Curriculum guidelines for the teaching of dentistry for handicapped persons have been prepared by a joint committee of the American Association of Dental Schools and the National Foundation of Dentistry for the Handicapped (19). It is most likely that new legislative authority would be needed.

C. Support for the remodeling of selected private dental offices and the upgrading of institutional dental facilities involved in providing care for handicapped people*

All long-term care institutions for handicapped people should be furnished with up-to-date dental equipment and supplies including items required for rendering treatment under general anesthesia or through inhalation sedation. Departmental grant support should be made available to states, in an amount proportional to the number of institutionalized handicapped in the state, for these purposes.

In addition, such support should be made available to states, in an amount proportional to the estimated number of noninstitutionalized handicapped people in the state, for communities wishing to remodel one or more dental facilities in that community for the purpose of making those facilities accessible to handicapped persons. New legislative authority would most likely be needed to initiate the programs described.

D. Changes in the Medicaid law and/or regulations*

Dental services for adults under Medicaid should be a required benefit in all states for all needy, handicapped persons including those who are "dentally indigent." Currently, the provision of dental services for adults is an optional service left to the discretion of the individual states.

Furthermore, the Department should encourage improvement in the remuneration paid to dentists for treating Medicaid patients. This may require an increase in the federal match paid to states for dental services.

E. Support for and implementation of dental health educational and informational programs for handicapped persons, health care providers, and others in contact with handicapped people*

An educational and informational program for handicapped persons, parents of handicapped children, persons who work with handicapped people on a regular basis, advocates, centers of independent living, and health care providers on the importance of regular dental care, proper methods of oral hygiene, and proper use or application of other dental disease preventive measures should be established. In addition, these persons should be informed of where handicapped persons may obtain dental services.

This program might be designed and coordinated by the Bureau of Education for the Handicapped, Office of Education.

F. Support of dental disease preventive measures*

Because the dental decay rate of children — including handicapped children — would be reduced substantially from consumption of fluoridated water from birth, the Department should make every effort to see that the Center for Disease Control

fluoridation program receives the support necessary to ensure the attainment of the program's goal of near universal community fluoridation in the United States.

Additionally, support for oral hygiene and supplementary fluoride programs (in non-fluoridated areas) for handicapped people is needed. These preventive programs can be effectively applied and monitored in most settings in which handicapped people are brought together as in special schools, sheltered workshops, independent living centers and long-term care institutions.

G. Provide support for the development and expansion of hospital and/or dental school based programs for handicapped people*

The hospital or dental school environment would appear to be an almost ideal one for providing dental services to severely handicapped individuals. Hospitals and dental schools have the necessary facilities for the diagnosis and evaluation of handicapped patients and for the provision of dental services under sedation or general anesthesia, if necessary. Initial efforts in this area should be geared toward the establishment of at least one hospital or dental school based program qualified to provide dental services for handicapped people in each Health Service Area in the United States in which such a program does not now exist. Care should be taken, however, to assure that hospital or dental school based treatment and the provision

of dental services under sedation or general anesthesia does not become the treatment of choice for those handicapped persons who can and should be treated in the community in private dental offices without such special attention, unless indicated.

H. Increased federal support of research and development relating to the oral health of handicapped persons*

Areas of research and development which should be supported include:

o Determination of the best mode of delivery of fluoride to handicapped people in areas lacking fluoridated community water supplies.

o Development of improved techniques of oral hygiene that could be used by handicapped people.

o Clarification of dental aspects of handicapping conditions, treatment methodology and patient management (including behavioral and pharmacological approaches).

o Development of standardized teaching aids and audio-visuals on the subjects of provider sensitivity, patient management and treatment, and typical encounters with frequently experienced disabilities.

o Evaluation of the effectiveness of dental school programs designed to train dental students to provide treatment to handicapped people (e.g. the recent pilot programs supported by the Robert Wood Johnson Foundation).

o Development of techniques to permit local areas to determine the likely universe of ambulatory handicapped persons. Types of disability, age, mobility, degree of self-sufficiency and income level of the handicapped — if these factors could be determined — would add to information needed to plan effective dental programs to reach the handicapped population.

o Documentation of the amount and degree of dental services delivered to the handicapped population by existing dental practitioners with the intent of establishing the predominant characteristics of participating providers, patients, services, comparative treatment times, and other factors of value in establishing reimbursement incentives.

o Determination of the various portable dental treatment systems now available with the intent on developing more efficient and less costly portable equipment that can be used with the homebound or institutionalized.

o Documentation of the degree of utilization of dental services by the handicapped population.

The suggested research could best be accomplished by the National Institute of Dental Research and the National Center for Health Services Research under existing authorities.

I. Federal support of training programs for faculty*

If training programs in the care of handicapped people are to be instituted in all or most dental schools in the United States, it will be necessary to develop a cadre of trained personnel to direct and administer such programs. In addition to clinical skills, such individuals should have special knowledge in the areas of administration, patient management, applied pharmacology, and the effective use of health personnel of multiple disciplines. At minimum, federal support for at least one dental school to establish a training program to prepare dental faculty to teach students to care for the nonhospitalized handicapped population is recommended. New legislative authority would be required.

J. Federal support of training programs for dental hygienists and auxiliaries

Because of the role para-dental personnel can play in providing treatment and preventive services to handicapped people, support for the development of special programs should be provided to schools for dental hygienists and auxiliaries to train students in the care and management of handicapped people, including elderly handicapped people confined to nursing homes. It should be recognized, however, that most, if not all, state dental practice acts prohibit the provision of

such services by para-dental personnel without the supervision of a dentist. New legislative authority would be required to implement this training program.

K. Provision of financial incentives for practicing dentists to attend continuing education courses

Many dental practitioners are reluctant to treat handicapped people because they have not been exposed to or received training in this area in their undergraduate dental studies. It is likewise difficult to persuade them to avail themselves of continuing education courses designed for this purpose. Incentives in terms of special tax deductions or financial support to attend such training courses would serve to increase the number of practitioners who feel competent to treat handicapped people. New legislative authority would be required.

L. Federal support of symposia, conferences, and workshops

The recent National Conference on Dental Care for Handicapped Americans supported by the Robert Wood Johnson Foundation has rekindled an interest in the dental care of handicapped persons that should be followed up with additional conferences on other approaches to improving access of dental care to handicapped people. All Departmental agencies and units with programs impacting on the oral health of handicapped persons should consider initiating and supporting such conferences. NIH, through its Consensus Development Conference approach, offers one possible avenue.

M. Directory of treatment and transportation resources

Federal support should be provided for the compilation and publication of a directory listing providers of dental services with the skill and desire to treat handicapped persons and what is known about available dental treatment and transportation support for handicapped people from the Federal Government and from all other sources on a state by state basis.

N. Centralized system of data collection, monitoring and evaluation

Existing Departmental dental programs for the handicapped are uncoordinated and lacking in adequate data collection, monitoring or evaluation, resulting in the inability to analyze effectively the results of existing programs or to plan new ones. A management information system that includes computer mapping would be useful in summarizing and depicting visually the relationships between the dental care access problems of handicapped people and program goals, dollars spent, treatment rendered, and health outcomes. Such reporting would permit analyses at national and regional levels by type of handicap, age group, urban/rural residence, and other factors. Analytical reports of this nature could be very informative in identifying program deficiencies and persuasive in obtaining Congressional support for appropriate legislation and funding. This activity might conceivably be a function of the Departmental focal point for activities relating to the oral health of handicapped people.

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